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ABSTRACT

South Carolina, a basically rural state, faces interrelated problems (housing, transportation, education, etc.) for 23,000 developmentally disabled individuals. These individuals are extremely vulnerable because of the lack of programs designed to meet their needs. Housing for the developmentally disabled remains very sparse and is often dilapidated. Educational programs for developmentally disabled individuals (who must leave school at age 21) have not been a problem for mildly retarded or handicapped persons because of adult education programs available in most South Carolina school districts. Through adult activity centers in small towns and rural communities, adult developmentally disabled individuals have opportunities to gain skills in vocational and academic education, though opportunities to earn money are very limited. Because one of the greatest needs is that of transportation, some means must be found to link transportation needs to unused available transportation. Two greatly unmet needs are therapy for developmentally disabled individuals and respite care for their families (for whom nothing has been done in small or rural communities). Although volunteers and local community service clubs have been most helpful, agencies with specified services need to be encouraged to look at new ways to meet needs. (BRR)

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INTERRELATED PROBLEMS OF THE DEVELOPMENTALLY DISABLED RESIDENT IN RURAL SOUTH CAROLINA

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INTERRELATED PROBLEMS OF THE DEVELOPMENTALLY DISABLED RESIDENT IN RURAL SOUTH CAROLINA

Of the almost 3 million inhabitants of South Carolina, about 23,000 have been identified as developmentally disabled. In a basically rural state many interrelated problems such as housing, transportation, education, etc., must be faced. These individuals are extremely vulnerable because of the lack of programs designed to meet their needs. Some programs are not extensive enough nor flexible enough to provide for needs and interrelated needs.

This paper proposes to examine in a limited manner the resources available and to offer alternative actions for meeting the needs of developmentally disabled individuals in a rural setting.

INTERRELATED PROBLEMS OF THE DEVELOPMENTALLY DISABLED RESIDENT IN RURAL SOUTH CAROLINA

South Carolina is one of the smallest states in the nation, containing only 30,000 square miles. It is basically rural in nature, with only six small to medium size cities located in it. South Carolina has a population of approximately 2,800,000 persons.[1] Of this population about 23,000 individuals have been identified as disabled.

The term, "developmentally disabled," is defined in Public Law 95-602, "Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978" as:

> The term 'developmental disabilities' means a severe, chronic disability of a person which:
>
> A) is attributable to a mental or physical impairment or combination of mental and physical impairments;
>
> B) is manifested before the person attains age twenty-two;
>
> C) is likely to continue indefinitely;
>
> D) results in substantial functional limitations in three or more of the following areas of major life activity: (i) self-help, (ii) receptive and expressive language, (iii) learning, (iv) mobility, (v) self-direction, (vi) capacity for independent living, and (vii) economic self-sufficiency; and
>
> E) reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated.[2]

In addition to the problems specified above in the definition, there are also a number of interrelated problems

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that the developmentally disabled individual must face. Included among these are: housing, education, transportation, therapy, and respite care, as well as others.

Those individuals who reside in rural South Carolina are at particular risk. They are extremely vulnerable individuals because of the lack of programs designed to meet their needs or programs that do not go far enough to provide for all of their defined needs and interrelated needs.

This paper proposes to take a very brief look at the alternative resources that may be available or that may be developed for these individuals in order that they may function on a higher level.

In recent years there has been a move for developmentally disabled individuals to be returned to the community from institutions. There is also a move to maintain such individuals in their own communities, rather than have them institutionalized. These new philosophies and their implementation have impacted on communities, particularly those in rural areas where resources are so scarce. This has imposed even more stress on those agencies that do exist. For example, the Department of Social Services in South Carolina now is charged with the responsibility of providing additional services for their clients rather than just monetary servies alone. One service is the medicaid program for which all developmentally disabled persons are eligible. In addition, the

Case Coordination Project of South Carolina has attempted to locate and to make linkage between the developmentally disabled and those resources that are available to them. They seek to provide services where there are none and will contract for such services from private individuals and agencies, if public agencies are not capable of providing such services.

The South Carolina Protection and Advocacy Agency provides service for all South Carolina developmentally disabled clients. Their goal is to represent anyone who has a need for protection or advocacy with other agencies or in the courts of South Carolina.

Housing. One of the primary needs of the developmentally disabled individual after he has reached his adulthood is that of housing. In recent years the Department of Housing and Urban Development has attempted to provide for individuals who are handicapped through its requirement that all new housing that is funded by HUD shall have a certain percentage of the housing set aside for the handicapped and for the elderly. This program in and of itself has given the developmentally disabled individual an opportunity for the first time to have suitable housing provided for them, since there must be free access to each of the units. Although this does not fully meet all the needs for housing of the developmentally disabled population, it does afford access to public housing.

Housing for the developmentally disabled is very sparse and of a dilapidated nature in rural areas. This type of housing is generally the only kind available to the developmentally disabled who are most often from low income families. Additional housing that is needed is rarely provided in rural areas for these persons since housing in general is very hard to come by in small towns or in rural areas.[3]

Since many developmentally disabled individuals are functioning in rural communities in a marginal way, they occupy very dilapidated housing. Often these persons are not identified as developmentally disabled but meet all the criteria of the developmentally disabled. Too often they are considered "lazy and ignorant" people who "don't try."[4]

There are a few residential housing developments being made available in the local communities for a few, eight to twelve persons, funded through the South Carolina Department of Mental Retardation in cooperation with Title XX funding. This housing is placed in rural communities or in small towns and made available primarily to those persons who are being deinstitutionalized. This type of housing involves the use of house parents or counselors who are available on a 24 hour basis.

Some new attempts have been made to development apartment complexes in small towns for the developmentally

disabled. This type of housing generally is under the supervision of the local retardation board of the county or a private retardation center. These apartments have been somewhat successful in providing independent living for the developmentally disabled, while at the same time providing supports through the resident managers that are assigned to them.

One other way that has been suggested, but has rarely been put into effect in rural communities, has been a boarding type home in which the developmentally disabled individuals are allowed to live and have their meals provided for them. These homes are almost the "old fashioned rooming-boarding houses" of years goneby, with an interested family serving the developmentally disabled individual as a "foster" family. These provide the developmentally disabled person a degree of freedom while providing food, housing and a supportive atmosphere.

Education. The developmentally disabled is able to receive an education under Public Law 94-142. This provides that they be given the type of education that is least restrictive for them. The developmentally disabled individual, at age 21, is no longer allowed to attend public school. However, with adult education programs available in most school districts in South Carolina, this has not been a particular problem for those individuals who are mildly retarded or handicapped in such a manner that they may continue

to learn. Adult education provides many remedial and vocational programs.

An example of this is a young man who had polio at a very early age and was not allowed to attend school by his parents and the school system made no provision for him. He is still unable to walk and meets the requirements of developmental disability. He is 37 years old and is unable to read or write. A volunteer in an adult activity center in a small rural town was able to assist this man in learning to write and help him learn to read. This has been for him the greatest accomplishment of his life. Although others thought that he might be interested in learning to walk as a primary goal for his life, this man indicated that learning to read was his greatest desire.

The use of volunteers has been demonstrated to be effective in assisting young adults who are developmentally disabled to learn. The one to one or small group approach enables them through the development of relationships to begin a learning process. It has been noted in some of the adult activity centers throughout the State in rural areas that these individuals tend to learn better than they did at an earlier age when they were attending public schools. This should be taken into consideration and a continued effort should be maintained to stimulate these individuals in order that they may function at their highest level.

Through adult activity centers in small towns and in rural communities, the adult developmentally disabled individual has an opportunity to gain skills in vocational education, as well as in academic education. Often this provides an opportunity for a feeling of self worth so necessary to those who feel that they are less than the "normal" individual.

An adult activity center set as learning goals for their clients personal grooming goals so the clients appeared cleaner and more attractive to the general public. It was a real accomplishment when all the men could shave themselves and all the women were able to shampoo their own hair. Through the grooming goals they were taught the appropriate clothing to wear. Many for the first time were interested in their personal appearance.

Most rural communities have few opportunities available for the developmentally disabled client to earn any money. One such community involved the developmentally disabled clients in washing used cars for an automobile agency, stuffing advertising sections in the local newspaper, and assisting a minister to move from one house to another. The activity center contracted for the jobs and divided the money among the developmentally disabled workers. For some this was their first income. The thrill of earning your own dollar and being allowed to do with it what you please often

triggers the desire for more jobs and more rewards. The community also has a learning experience: Seeing those persons working under supervision whom they thought would never work.

Transportation. Perhaps one of the greatest needs of all in rural areas is that of transportation. Most rural areas lack all forms of transportation. The only available transportation is the private automobile. Since few of these individuals have access to this type of transportation, it is vital that they have some mode of transportation available to them. There are no buses serving these rural areas locally, nor are there any rapid transit railroads or anything of this type. The individual has only a few alternatives available to him. One of these is the family owned automobile. Many times the use of this type of transportation is quite difficult for the individual who is in a wheel chair or on crutches or is unable to walk at all. The parents or other family members need to be trained in assisting the individual in the use of private transportation. If the individual is capable of learning to drive through the use of some type of modified vehicle, he should be encouraged to do so, since it provides for him a sense of freedom , as well as providing transportation.

One young man was able to pass his driving test

and obtain a license. His parents accompanied him as he drove for many years. Now his parents are elderly and unable to drive themselves and he has become the responsible driver for the family.

The only form of transportation in rural areas is that form of transportation provided by agencies. The local Department of Social Services often times provides transportation to health departments or for some very needed transportation for therapy. However, there is little transportation provided for shopping to obtain food, clothing or essentials. The developmentally disabled individual has almost no form of transportation available to him to allow him to participate in any kind of community activities.

One of the suggested forms of transportation in rural areas would be the use of school buses during those hours in which they sit idly by while children are in school. This would probably necessitate the changing of the laws in South Carolina in order to do this, but it is one possible way.

Local adult activity centers provide transportation for shopping for the members of their centers. Often times this type of center is not available on a wide enough basis to provide for all of the developmentally disabled individuals' needs in the community through their program. Should there be other agencies in the community, such as the Commission on Aging or the Department of Health and Environ-

mental Control, they too might furnish transportation through pooling of their vehicles.

Service clubs and organizations seem to abound in small rural towns in South Carolina. Volunteers from them might be one means of helping stimulate an interest in providing transportation for the developmentally disabled.

A church purchased a van for the use of its congregational programs. One suggested use of this van was to carry its elderly and infirmed grocery shopping. Not one person availed himself of this service. Some means needs to be found to link the developmentally disabled with needs for transportation to those who have private transportation that is unused. Communication lines need to be established particularly in rural areas to meet unmet needs.

Therapy and respite care. Often the developmentally disabled individual has a tremendous need for speech therapy, physical therapy, occupational therapy or recreational therapy and does not have this available to him locally. It remains to interested individuals in local communities to assist the individual with these needs to obtain the necessary services. While therapist are available readily in large urban areas, there are very few located in rural areas. The use of individuals who are willing to participate in the establishment of clinics for such therapies in their own communities tends to happen within rural areas because of the strong sense of

community that develops there. Sponsorship by clubs and organizations might also entice therapists into these areas to provide services for the disabled.

Respite care for the parents of the developmentally disabled child or respite care for the family of developmentally disabled adults is a tremendous need that has yet to be met in rural areas. There is no one to take over for any length of time, either on a weekly basis or even for a few hours. While this need can be met in large urban areas, nothing has been done to assist the families of the developmentally disabled in small towns and in rural communities.

A man in his forties has Down's Syndrome. His mother is in her late seventies and has many severe physical ailments. She was hospitalized. Because there was no other close family members and because the mother was so fearful of "losing" her son, this man spent all his time in his mother's hospital room. He is unable to prepare food for himself so that during this time he had to be fed by friends and the nursing staff. This is a prime example of a need for care for a brief time, even if the mother is unable or unwilling to tolerate a more lengthy separation.

Summary. We have pointed out the need in rural areas for volunteers to spearhead drives to find resources for the developmentally disabled in their own rural communities and small towns. Agencies with specified services need

to be encouraged to look at new ways to meet the needs of housing, transportation, education, et cetera, for the developmentally disabled and to make creative use of any transportation available to them, as well as any services that they may be able to provide for the developmentally disabled. Needs are still much in evidence and few solutions have been found to assist those people who are most vulnerable.

South Carolina will continue to move to care for its developmentally disabled because any awareness that is brought to the attention of the public elicits grass root support from all areas. This is evidenced by the number of adult activity centers that have been so successful in rural areas in providing services for the developmentally disabled in those areas. These adult activity centers have opened up new avenues of education, vocational education, and self-functioning in order to promote a higher level of functioning of the developmentally disabled throughout the rural communities. In addition, the whole community itself has supported through their contributions to United Way and through the use of local county government sponsorship these agencies.

The local community service clubs and organizations and churches have been wholeheartedly behind programs for the developmentally disabled in South Carolina and have made great strides in trying to find and meet the needs of these individuals.

Notes

1. 1980 South Carolina Legislative Manual, Lois T. Shealy, Editor, Columbia, S. C.

2. Public Law 95-602 "Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978."

3. Robinson, Halbert B. and Robinson, Nancy M. The Mentally Retarded Child (New York: McGraw-Hill Book Company, 1965)

4. Rogers, Everett M. and Burdge, Rabel J. Social Change in Rural Societies (Englewood, New Jersey: Prentice-Hall, Inc., 1972)